

POSTER PRESENTATION

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Living with OI = Osteogenesis imperfecta = brittle bone disease

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Osteogenesis imperfecta (“OI” or “Brittle bones”) is a rare genetic disorder of the connective tissue characterised by bone fragility. Other symptoms that may occur are: short stature, hearing impairment, skeletal deformities, loose joints or fragile teeth.

At present OI cannot be cured. Treatment is aimed at preventing or correcting its symptoms and at the best living conditions possible for OI-people. This usually involves orthopaedic surgery, steel rods, physiotherapy, possibly the prescription of certain drugs (bisphosphonates), sometimes hearing or dental treatment. Mutual support through the exchange of experience and information is of prime importance, both for those affected and for their families. More than 40 OI societies worldwide take care of this today.

Founded in 1993 OIFE is the federation of national European OI societies. In 2010 OIFE has 18 European member societies and six associated non-European members in Australia, Ecuador, Mexico, Peru and North-America.

Services of the OIFE include:

- Representation of its members and on a European level, e.g. as a member of EURORDIS, sometimes even worldwide,
- Presentation of problems, needs and expectations of people with OI to national and international organisations,
- Support for yearly international OI-youth-meetings
- Networking between professional OI-specialists and treatment centres, national OI associations and OI patients worldwide

- Promotion of research on all aspects of OI, in cooperation with an international OI-registry based in the US
- Collection and publication of information about OI
- Support of member-societies by the exchange of information and experience
- Promotion of public awareness of OI
- Education for doctors and other professionals by the organisation of international conferences, topical meetings and workshops
- Support and coordination for international Student exchange for young OI people

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